Trends in Education

Trends in Residential Institutions for the Mentally Retarded

by

Philip Roos



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Minnesota State Planning Agency 300 Centennial Building 658 Cedar Street (St. Paul, Minnesota 55155

by

Philip Roos Executive Director National Association for Retarded Citizens

People have relatively little tolerance for deviance from cultural values and cherished patterns. Those who fail to conform to cultural values are labeled "deviant" and become subject to culturally determined responses. These responses, all too often, increase the potential for deviant behavior. Since our society places high value on intelligence, it is not surprising that persons whose cognitive skills are obviously inferior have traditionally been stigmatized and excluded from the main-stream of society.

Mental Retardation

Mental retardation is currently used to refer to a wide variety of deviance characterized by a difficulty in complying with intellectual norms and culturally determined social behavior. Although specific definitions differ from country to country, there is general agreement that a diagnosis of mental retardation is based on multiple criteria, including measured intelligence (usually quantified as an Intelligence Quotient), adaptive behavior level (sometimes quantified as a Social Quotient), and medical classification (Roos, 1969d).

More than 250 causes of mental retardation have been identified to date, yet in approximately 75% of cases no specific etiology can be determined (The President's Committee on Mental Retardation, 1971). Levels of retardation vary from extreme impairment in which the individual is practically helpless to relatively minor deviation from cultural norms. The American Association on Mental Deficiency recognizes four levels of mental retardation which are based on the degree of deviation from the mean. These levels of retardation, their approximate demarcation on a standard test of intelligence (the Revised Stanford Binet), and terms in common use in older texts and occasionally still found in the literature are summarized in Table 1 (based on Heber, 1961).

Estimates of the incidence and prevalence of mental retardation in the United States vary considerably among investigators (Heber, 1970; Lapouse S Weitzner, 1970). Although differences in definitions of mental retardation as well as in survey procedures influence the results of these studies, the most widely accepted conclusion regarding incidence of mental retardation in the United States is that 3% of the population will at some time in their life function at some level of mental retardation. Hence, more than 6 million Americans fall within this group (Tarjan, et al, 1973). Evidence indicates, however, that the prevalence of mental retardation is significantly lower. No more

Table 1 Levels of

Measured Intelligence

Current Term	Range in Standard Deviation Units	Revised St. Binet I.Q.	Equivalent Terms in Older Usage
Borderline Retardation	-1.01 to -2.00	83 - 68	Borderline
Mild Retardation	-2.01 to -3.00	67 - 52	Moron-Educable
Moderate Retardation	-3.01 to -4.00	51 - 36	Imbecile-Trainable
Severe Retardation	-4.01 to -5.00	35 - 20	Imbecile-Trainable
Profound Retardation	€5,01	20	Idiot

than 1% of the population, or 2 million Americans, are technically mentally retarded at any given time (Tarjan, 1973). This discrepancy between incidence and prevalence is attributable to the fact that the diagnosis of mental retardation is related to age and that the mortality rate is higher for seriously retarded persons than for the average population. Hence the peak period of identification is between the ages of 6 and 12, and about two-thirds of the individuals diagnosed as mentally retarded lose this label during late adolescence or early adulthood.

Early Developments

Retarded persons have traditionally been shunned, rejected, ridiculed and isolated from society (Kanner, 1964). Following the pioneering efforts of Itard in the 1800's (Kanner, 1964), early workers built residential institutions and provided education designed to prepare their residents for a productive life in society.

The historical development of residential institutions in the United States has reflected changing approaches to deviance (White & Wolfensberger, 1969' Wolfensberger, 1969a). During the early stage of optimism and habilitative efforts (1850-1880), institutions attempted to make the deviant "undeviant." Such early pioneers as Seguin, Wilbur and Howe in the United States and Guggenbuhl in Switzerland developed programs aimed at educating the retarded so that they might be able to return to society.

Early optimism gradually dissipated as the promised results failed to materialize. Institutions grew as they accumulated a residue of

non-habilitated residents. Institutional programs became concerned with effective isolation, economy of operation, and maximum use of resident labor. By the late 1880's the philosophy of institutions had shifted from one of returning individuals to society to one of protecting the deviant from society.

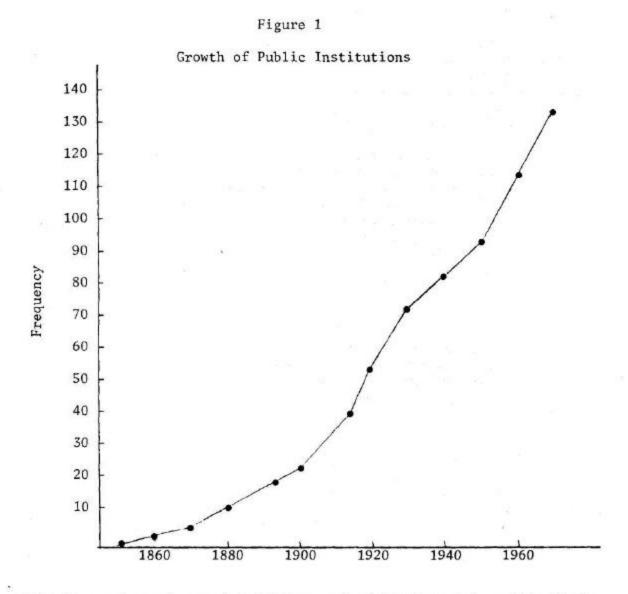
This phase was soon replaced by custodial warehousing aimed at protecting society from the deviant (1880-1925). Genetic studies allegedly linking mental retardation with forms of antisocial behavior (Goddard, 1914) produced a concern for controlling and containing the retarded through institutionalization. Programs, which would now be described as dehumanizing, were advocated by most leaders in the field, including Fernald, Powell, Carson, and Barr.

The impact of ideologies regarding the mentally retarded which evolved during these early phases of institutional development cannot be overemphasized. Wolfensberger (1972) has described several destructive models of mental retardation held during this time and their influence on services for the retarded. Among these models, the following were particularly common:

- 1. The subhuman organism the retarded are viewed as not fully human, and hence as devoid of many of the needs, aspirations and sensitivities of other human beings. Their human and legal rights can therefore be curtailed or ignored. They are allowed minimal freedom and are managed much as animals.
- 2. The menace the retarded are viewed as a threat to society because of their propensity for crime or because of their genetic danger to society. They must, therefore, be contained and isolated, Services and facilities are designed to protect society and may incorporate punitive elements.
- 3. The object of pity the retarded are viewed as "suffering" and are benignly nurtured and sheltered. Emphasis is placed on keeping them contented, but they are not treated with respect or dignity.
- 4. The eternal child the retarded are viewed as persons who will always be much younger than their age. Their interests and needs are childlike and hence they should be protected from developmental demands. Services based on this model tend to overprotect the retarded and to stress entertainment and a "happy" state of affairs.
- 5. The diseased organism the retarded are perceived as sick and in need of "treatment" and "hospitalization." Dependency, safety, cleanliness, and comfort are stressed with emphasis on medical services.

Trends in Institutional Population

The number of institutions has grown considerably since the first permanent United States institution was established in Massachusetts in 1848. Figure 1 (Baumeister, 1970, Fig, 1-1, p. 18) presents the growth of public institutions for the retarded. The latest data supplied by the United States Department of Health, Education, and Welfare (HEW, 1972) indicate that the number of public institutions had increased from 108 in 1960 to 190 in 1970. Rosen & Callan (1972) reported 202 in 1972. In addition, HEW listed 708 private facilities for the retarded in 1970.

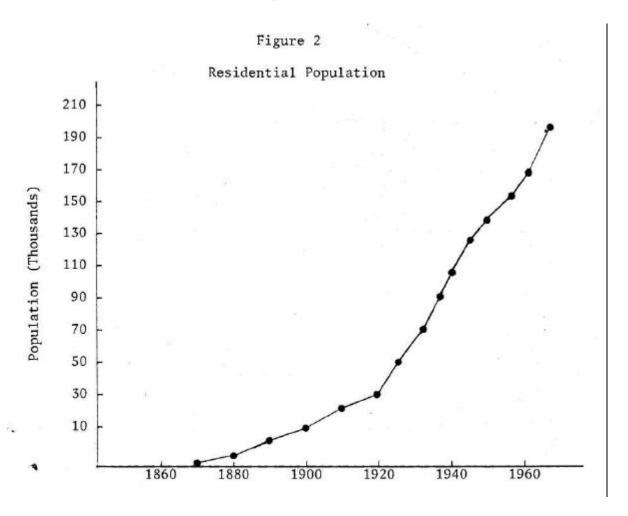


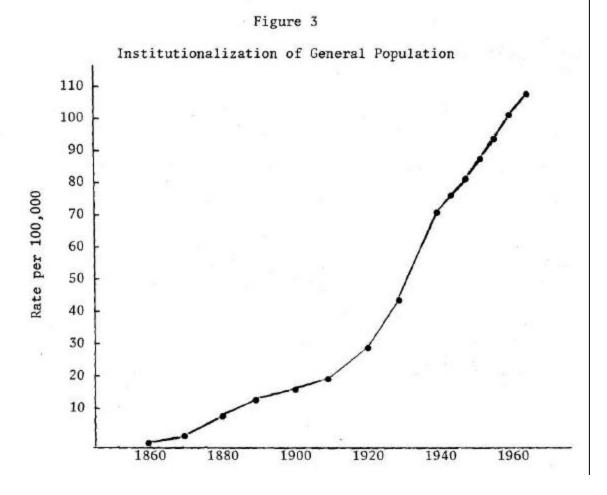
The number of retarded children and adults housed in public facilities has likewise increased markedly. Figure 2 (Baumeister, 1970,

Fig. 1-2, p. 19) depicts the growth in population of public facilities. Figure 3 (Baumeister, 1970, Fig. 1-3, p. 19) presents the increase in the rate of institutionalization per 100,000 population (Baumeister, 1970). More recent data from HEW (1972) indicate that the institutional population peaked in the mid-sixties and has been declining since. The number of residents per 100,000 population rose from 91.9 in 1960 to 98.8 in 1966. The rate then decreased gradually to 94.2 in 1970. Likewise the number of first admissions increased from 7.6 in 1960 to 7.8 in 1965 and then began a gradual decline to 6.2 in 1969. A 1972 survey of state institutions for the retarded (Rosen § Callan, 1972) likewise revealed that 72% of state institutions indicated a decrease in their population over the past five years due to Community placement activities.

Public institutions for mental retardation housed approximately 190,000 residents, or 75% of the total number institutionalized in 1969 (HEW, 1972). State mental hospitals included 32,000 mentally retarded residents, or 12% of the total, and private institutions for the retarded contained the remaining 13%, or approximately 33,000 retarded persons.

By the mid-sixties, 82% of the residents in public institutions for mental retardation had I.Q.s below 50 and approximately 50% were below the chronological age of adulthood (Butterfield, 1969). Approximately 80% of first admissions were under 20 years of age (Baumeister,





1970), There seems to be general agreement that admissions to institutions are getting generally younger and more seriously impaired. Wolfensberger (1971a) predicts a decline in the incidence and prevalence of severe and profound retardation. Factors contributing to this prediction include reduction in the birthrate of high risk groups, improvement of health services, increased use of abortion, general improvement of the environment, and increased early childhood education. Conversely, Wolfensberger concludes that the prevalence of the aged retarded is likely to increase, primarily because of increasing life expectancy.

Institutions are seriously overcrowded (The President's Committee on Mental Retardation, 1968; Kugel § Wolfensberger, 1969). Data collected in 1968 suggested that institutions would have to expand by more than 25 percent to eliminate their waiting lists for admission (Butter-field, 1969). According to Baumeister (1970) the average waiting period for admission in 1968 was two years in most states and as long as five or six years in some states. Since there were at least 31,000 individuals on waiting lists and only 9,000 residents were released annually and 3,000 died, there were 2.5 persons waiting for every vacancy that became available.

The gradual increase in expenditures for residents of state institutions suggests improving conditions. HEW (1972) reported an average per resident per day expenditure of \$4.20 in 1960, compared with \$11.64 in 1970. Whereas the minimum spent by a state per resident per day was \$1.63 in 1960, this amount had increased to \$4.61 in 1970.

Most state institutions are large multipurpose facilities. In 1969, over one-half housed more than 1,000 residents. A recent trend toward smaller institutions is evidenced by data which show that three-fourths of the public institutions built between 1960 and 1969 were intended for 500 or fewer residents (Butterfield, 1969).

Disillusionment

These recent trends, including increases in facilities, better funding of institutions, and lower rates of institutionalization would suggest a significant improvement in services to the retarded in state institutions. This conclusion does not seem warranted, however, in view of the mounting dissatisfaction being expressed by professionals, consumer groups, and interested citizens. Criticisms of state institutions and demands for reform have become increasingly virulent during recent years.

- Dehumanizing conditions which violate human dignity and basic legal rights of residents. The lack of privacy, gross over crowding, absence of personal property, arbitrary scheduling of daily activities, enforced idleness, extreme regimentation, restriction of freedom, inappropriate groupings of residents, inadequate physical facilities, and primitive and restrictive practices are among the specific conditions often listed as contributing to dehumanization.
- 2. Unsanitary and hazardous conditions, which endanger the health and safety of the residents. Inadequate medical and nursing staff, improper use of medication, poor nutrition, fire hazards, prevalence of dirt and vermin, massive over crowding, dearth of staff supervision, and inadequate main tenance of equipment and physical plant have been documented as common in some institutions.
- 3. Conditions contributing to regressive and deteriorative changes in residents. Many institutions have failed to pro vide educational and training programs, including occupational therapy, physical therapy, language development, counseling, vocational preparation, and other essential services to large segments of the population. Systematic comprehensive evaluations and periodic re-evaluations are lacking or incomplete

for many residents in some institutions. Individual program plans designed by multidisciplinary teams are seldom designed for all residents of any institution. Lack of stimulation is often coupled with an impersonal environment devoid of intimate relationships. The destructive impact of these conditions is further reinforced by factors which foster dependency, submissiveness, and apathy.

- 4. Self containment mitigating against return of residents to community living. Many institutions have become isolated from the communities which they allegedly serve, and little effort has been directed at articulating institutional services with those offered by other community agencies. Programs designed to equip residents for community living are frequently absent or rudi mentary. Conditions in some institutions insidiously reward residents for adopting passive, docile, and submissive patterns of behavior which decrease their likelihood of adapting to society.
- Exploitation of residents. Use of residents as an unpaid (or minimally paid) institutional labor force has been common prac tice in many state institutions. Some facilities would not until recently, have been able to operate without using this type of labor. In some cases the institution's more capable residents have been re tained as "institutional workers" rather than prepared for community discharge. Another form of exploitation consists of using institutional residents as subjects of research. Only in recent years have policies and procedures been developed to safeguard the resident's welfare when involved in research (American Association on Mental Deficiency, 1969; HEW, 1971). The efficacy of these procedures, however, is questionable. As recently as April, 1973, the Pennsylvania Association for Retarded Children initiated action against the state's institutions which resulted in a moratorium on all research using residents of state institutions for the retarded.

The mounting dissatisfaction with institutions for the retarded has been reflected in recent years by the publication of several influential books which have dramatically presented some of the conditions just summarized. In his excellent book, Exodus from Pandemonium, Blatt (1970) includes an annotated bibliography of works describing abuse in institutions for the mentally ill and mentally retarded. Several of these works have had major impact on professionals, administrators, and consumer groups.

Vail's (1966) analysis of the dehumanizing impact of institutional settings was one of the early, clearly stated condemnations of institutions. Vail documented that, because of the need to cope with large masses of people, most institutions develop regimented programs aimed at the "least common denominator." The result of such programs is a loss of individuality for residents.

Blatt and Kaplan's (1966) dramatic photographic essay of institutions for the mentally retarded had a major impact on administrators and professionals, and the subsequent pictorial version appearing in Look (1967) aroused the general public. By confronting the reader with photographs of the deplorable conditions existing in contemporary state institutions, Blatt helped strengthen the growing spirit of reform. By contrasting conditions in the "back wards" of large institutions with constructive conditions in small state-operated regional center facilities, his work emphasized that viable alternatives do exist and that positive change is possible.

Research Findings

The detrimental effects of institutionalization have been documented in the research literature. Klaber (1970) summarized research on institutional rearing by concluding that:

- 1. Institutional child rearing is generally less conducive to child growth and development than normal home care.
- 2. Some institutional environments are less harmful to child growth and development than others (p. 165).

Although data suggest that, in general, children develop less rapidly in institutions than in their own homes (Butterfield, 1967), it seems that the greater the child's deprivation in his own home, the less damaging the institutional effect (Zigler, 1961, 1966). Findings also indicate that the younger a child is placed in an institution, the more vulnerable he is to its detrimental effects (Butterfield, 1967).

The quality of programs within institutions can greatly influence the development of their residents. Skeels (1966) demonstrated, for example, that short-term institutionalization under conditions of intimate interpersonal involvement in childhood may lead to fully productive adult living. Studies suggest that institutional effectiveness depends on a high degree of human interaction among the residents as well as between residents and staff (Zigler, 1966; Klaber, 1969). Increasing the ratio of attendants to residents apparently does not necessarily improve the degree of interaction (Thormahlen, 1965; King and Raynes, 1968). An increase in professionals and volunteers, however, does result in more interaction. Unit-size seems more important than the attendant-resident ratio (Klaber, 1969).

Relatively little research has been aimed at evaluating the effectiveness of institutions or the quality of their services. The first major evaluative study of United States institutions was conducted by the American Association on Mental Deficiency (AAMD), Division of Special Studies (Hubbard, 1969) from 1966 to 1969. Using standards developed by the AAMD in 1964 (AAMD, 1964), evaluation teams conducted careful assessments of 134 institutions (out of a possible 168) which

voluntarily requested the service. Findings generally revealed conditions far below minimum acceptable standards. For instance, more than 50% of the facilities housing 62% of the residents living in institutions were rated as below standard; 60% of the institutions were rated overcrowded; 83% failed to meet professional staffing ratios; 60% lacked adequate space for educational, vocational and recreational programs; 60% had inadequate sleeping, dining and toileting areas; and 74% were forced to use residents as institutional workers.

Obstacles to Change

In spite of the general criticism of institutions for the mentally retarded in recent years and the accumulating evidence of their ineffectiveness, little real change has occurred in many states. As recently as 1973, conditions approximating those described by Blatt in Christmas in Purgatory (1966) could be found in many state institutions. Professionals, administrators, consumers, and legislators seem to be in general agreement that such conditions are intolerable and must be eradicated. Some states, however, are continuing to design new institutions which incorporate many of the features which have been identified as contributing to the destructive impact of institutions. Obstacles to institutional reform have recently been identified by several authors (Dybwad, 1969; Roos, 1970a). Some of the major factors impeding change include the following:

- 1. Fiscal resources have been serious limited and, in spite of gradual increases in institutional budgets, the institution's needs continue to seriously outdistance available resources. Staff shortages, inadequate physical plants and other limitations curtail many desirable changes and program innovations. Because of anticipated fiscal limitations new institutions are designed to optimize efficiency of operation rather than improve the effectiveness of services (Roos, 1969a). Hence, new institutions are still being designed to house congregate masses of residents in order to facilitate staffing patterns and minimize costs.
- 2. Destructive ideologies based on misconceptions of mental retardation (Wolfensberger, 1969a, 1972) continue to prevail among the general public as well as among some professionals and administrators. Some of these ideologies foster isolation and confinement of retarded persons and impede the implementation of institutional decentralization. Furthermore, continuation of dehumanizing practices has been rationalized by some on the basis of a sub-human model of mental retardation.
- 3. The geographic isolation of many of the older facilities has fostered their relative separation from the communities which they serve. Recruitment of professionals has often been difficult as a result of location. Articulation with other community

- services has been impractical. Unfortunately, some new institutions are being built in equally isolated areas.
- 4. A different type of isolation has resulted from the tendency to separate institutional services from other community services.

 Dichotomizing institutional services and other services, and labeling the latter as "community services," has tended to foster institutional self-containment and reluctance on the part of institutional staffs to develop broad community services.
- 5. Institutions have traditionally operated as monolithic organiza tions characterized by authoritarian management CRoos, 1970a). The typical management style, use of power, and communication structure have fostered maintenance of the status quo. In many institutions the superintendent has retained considerable power and relied on a management style of benign paternalism (Blake and Mouton, 1964). Decision-making has often been autocratic, and communication has been primarily unilateral with minimal opportunity for feedback,
- 6. Some institutional administrators are motivated to protect the system within which they operate. Their administrative decisions are likely to be determined by the need to protect existing practices, procedures, and traditions. Continuation of the existing system is often justified on the basis of past fiscal investments. Abandoning unsuitable buildings may, for example, be rejected on the basis of the original investment and accumu lated maintenance costs.
- 7. Bureaucracies are extremely resistant to change because of self-protective policies and practices and because of the vested interests CRoos, 1969a). Administrators tend to foster their own security by minimizing risk. The successful administrator is able to maintain a tenuous homeostasis within the institutional system. Any change endangers the existing balance of power. Administrative decisions may often be based, therefore, on the goal of minimizing internal conflict and potential risk.
- 8. Some administrators are strongly motivated by the need for self-aggrandizement or personal upward mobility. This need fosters empire-building strategies such as enlargement of management staff and proliferation of policies, manuals and procedures. The resulting bureaucracy is likely to lead to "hypertrophy of the superstructure" which seldom results in improved services to the retarded (Parkinson, 1957; Roos, 1969a).
- 9. Development of technocracies has been popular among adminis trators motivated by the goal of increasing the power and status of their own profession. Technocratic management monop olies are usually rationalized on the basis of the following "pseudo-syllogism to power" (Roos, 1969a, 1970a): (1) mental

retardation is a ... (medical, psychological, educational, etc.) problem; (2) only ... (physicians, psychologists, educators, etc.) can cope with ... (medical, psychological, educational, etc.) problems; (3) therefore, only ... (physicians, psychologists, educators, etc.) can administer mental retardation programs. This type of pseudo-logic is applicable regardless of the specific profession making a bid for power, depending on the specific definition of mental retardation which is selected. One of the unfortunate consequences of the resulting management monopolies is that genuine multidisciplinary cooperation is stifled. Members of professions not currently "in power" are likely to avoid commitment to mental retardation services. Indeed, medical models of mental retardation services have been particularly criticized, since the medical profession has tended to be most active in attempting to establish its jurisdiction over mental retardation programs (Roos, 1971; Wolfensberger, 1972).

- 10. Institutions typically include at least three distinct subcultures: (1) "administrators," (2) "professionals," and (3) "workers" (primarily direct care staff and such supportive staff as food-service workers and maintenance staff) (Roos, 1970a). Each of these sub-cultures has its own values, goals, and traditions. Communication among the three groups is often tenuous and at cross-purposes. The "progressive" philosophy enunciated by administrators and/or professionals may not be translated into direct services to residents because of resist ance by direct care personnel. Evidence that attendant attitudes remain essentially unaffected by inservice training programs (Klaber, 1970) underscores the serious difficulties encountered in implementing institutional change.
- 11. Often the bureaucracy within which the institution operates is itself a serious obstacle to change. Sophisticated management systems, such as Planning, Programming, and Budgeting Systems (PPBS) and Program Evaluation and Review Techniques (PERT), may become so cumbersome that they impede rather than catalyze progress. The state bureaucracy frequently introduces a lengthy delay between formulation of a plan and its implementation. The need for review and approval by state bureaus outside the agencies responsible for direct services to the retarded may result in delays generated by interagency communication problems.
- 12. Merit or civil service systems can be another obstacle to change. Since many of these systems entail rigid job descriptions and requirements, recruitment of scarce professionals and establish ment of new types of positions are often lengthy and difficult processes. Civil Service systems have also tended to reward tenure rather than accomplishment, so that promotion into leader ship positions has often resulted from longevity rather than demonstrated leadership capacity. As a result, innovative and

creative persons are likely to leave in frustration while longterm, traditionally oriented employees rise into supervisory and administrative positions. The Peter Principle (Peter and Hull, 1969) has considerable relevance to the dynamics frequently associated with leadership development in typical state systems.

Changing Ideologies

Future trends in institutional services will bear the imprint of recent ideological changes. The growing dissatisfaction with institutional programs, documented above, has generated a series of major national and international efforts to reorient residential services for the mentally retarded. In 1968 the National Association for Retarded Citizens (NARC) delineated operational objectives for residential services. These objectives were widely distributed and generally endorsed by administrators, professionals, and consumer organizations. NARC held a national conference on the same topic in 1969 to further disseminate its objectives and to involve state program administrators and institutional superintendents in implementing needed institutional reform (NARC, 1969). Manuals containing detailed quidelines and standards (NARC, 1972) were subsequently developed by NARC to assist state and local units in working constructively with institutional and agency administrators in improving residential services. Meanwhile developments in residential services were regularly reported by NARC through its special newsletter on residential services, The Record (NARC, 1960-1973).

Somewhat parallel efforts were mounted by the President's Committee for Mental Retardation (PCMR), a committee composed of 21 presidential appointees with professional staff support. In a landmark volume, Changing Patterns in Residential Services for the Mentally Retarded (Kugel and Wolfensberger, 1969) the PCMR dramatically described current problems in residential services and presented alternative models for addressing these problems. This volume had wide influence and became the focus of considerable controversy among professionals and administrators. In a subsequent publication (PCMR, 1970) the PCMR joined the NARC in proposing specific action steps to revamp residential services.

The international extent of the concern with institutional services was highlighted by a major symposium held by the International League of Societies for the Mentally Handicapped (ILSMH) in 1969. The resulting publication, Residential Care for the Mentally Handicapped (Roos, 1969c), summarized major areas of agreement regarding residential services among the thirteen member societies of ILSMH which participated in the Symposium. Although complete consensus was not reached on all issues, major areas of agreement emerged which reflected basic ideological agreement.

These major efforts to modify the premises basic to residential services for the retarded were paralleled by extensive publication in professional journals and books.

The new ideology for residential services which emerged from these activities has already begun to modify institutions and it promises to continue to reshape their future development. Principal tenets of the new ideology include the following:

Retarded persons should be viewed developmentally, capable of growth and learning, regardless of level of retardation or age.

This developmental model of mental retardation has been contrasted with destructive models by Wolfensberger (1969a, 1972). It has also been expanded and applied to programmatic and administrative issues by Roos, McCann, and Patterson (1970). According to these authors, programs for retarded persons based on a developmental model have as their principal goals: (a) increasing the complexity of the individual's behavior, (b) increasing the individual's control over his total environment (including his own body), and (c) optimizing each person's human qualities, as defined by the culture of which he is a member.

The general acceptance of the developmental model is reflected by the conclusion of the ILSMH (Roos, 1969c) that:

The most appropriate model of mental retardation is a developmental model, according to which retarded children and adults are considered capable of growth, learning, and development. Each individual has potentials for some progress, no matter how severely impaired he might be.

The basic goal of programming for retarded individuals consists of maximizing their human qualities, and as such is identical with the goal of educating and socializing normal children and young adults. The adequacy of programs as well as of physical environments can be evaluated in terms of the degree to which they fulfill this goal (p. 12).

This model leads to rejection of the once-popular concept of "custo-dial care," which is predicated on the assumption that certain individuals are essentially incapable of development. The model also cautions against labels which are likely to generate self-fulfilling and self-limiting prophesies (Roos, et al, 1970). By emphasizing concrete program goals, the model encourages program evaluation based on assessment of outcomes.

Retarded persons should live like non-retarded persons to the greatest degree possible.

Bank-Mikkelsen (1969) and Bengt Nirje (1969) first enunciated this general tenet as the "normalization principle." Nirje's definition has been most widely quoted: "...making available to the mentally retarded patterns and conditions of every day life which are as close as possible to the norms and patterns of the mainstream of society." (p. 181).

This principle has gained considerable popularity in the United States during recent years. It has become the principal guideline for formulating service delivery systems of all types, including residential services.

One of the basic premises of normalization is that behavioral deviance can be reduced by minimizing the degree to which persons are treated differently from "normal" persons.

The early definitions of normalization stressed the importance of using normative procedures and settings in programs for retarded persons. Hence, the principle dealt with normalization as a process rather than as an outcome. Yet, as Roos (1972b) has stated, "adherents of normalization may have inferred that normative procedures would yield normative outcomes, but this assumption does not necessarily follow logically nor has it been fully established empirically Cp. 146). This distinction between normalization as a means for reaching desirable goals and its adoption as a goal in itself was recognized by the following conclusion of the ILSMH (Roos, 1969c): "Normalization techniques which have proven very successful with most retarded children and adults may be modified to the degree that such modifications are more successful in developing normalized behavior in individual retardates " (p. 24).

Wolfensberger (1972) has recently expanded the definition of the principle of normalization to include both process and goal. He defines normalization as "utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible " (1972, p. 28). In applying this broadened definition to residential services, Wolfensberger (1972) describes five major implications of normalization:

- 1. Integration: This principle "...demands that residential services, like all services, generally need to be community-integrated and dispersed so that residents will intermingle with typical citizens in typical activities" (Wolfensberger, 1972, p. 8). Hence the location, size, and accessibility of residential services become critically important.
- 2. Smallness: Residential facilities need to be small to ensure that communities can absorb their residents effectively. Large facilities are criticized as fostering "dehumanizing management" and "inward rather than outward direction of both resident and staff socialization" (Wolfensberger, 1972, p. 81).
- 3. Separation of the domiciliary function: This principle "... demands that as few central services as possible be provided as part of a residential unit.... Residents should go to regular community resources and services..." (Wolfensberger, 1972, p. 83). Grouping of services within a single building,

or even on the same "campus" should be avoided if at all possible, since normative patterns clearly separate residential from other types of services.

- 4. Specialization: Residential facilities designed to serve specific types of residents help to separate the domiciliary function, as well as serve to separate age groups, and groups requiring different types of environments. Wolfensberger (1972) points out that specialization "...imposes the medi cal model only upon those who definitely need it. Further specialization reduces other undesirable types of hetero geneity of client groups.... In many of our institutions, those who need detention or a high degree of structure and supervision are housed in the same living units as those who do not, but because of the needs of the less advanced residents, all residents are subjected to a high degree of structure, supervision, and perhaps even detention " (p. 83).
- 5. Continuity: This principle refers to the necessity for continuity among different types of residences, and between domiciliary and nondomiciliary functions. According to Wolfensberger (1972), "a continuum of living facilities will provide many more options than exist now so that individuals can be moved along the continuum of supervision as needed, in either direction " (p. 84).

Consumers and their representatives should be maximally involved in planning, programming and decision making.

The development of such voluntary consumer organizations as the NARC was stimulated by inadequacy of services, popular apathy, professional mishandling and the hope by parents that their handicapped children could be helped (Roos, 1970b). These organizations have steadily gained in strength so that in recent years they have become a significant force for social change.

Increasing consumer participation in the planning and monitoring of services is being paralleled by growing consumer sophistication and expertise. Voluntary organizations, such as NARC, have developed systematic training programs designed to train their own members to function effectively as program planners and evaluators. In 1972 NARC developed a sophisticated curriculum and set of manuals to prepare parents and other consumer representatives to evaluate the adequacy of residential facilities and to work constructively with administrators in implementing change.

With increasing consumer expertise myths which were shared by many professionals and their clients are rapidly fading (Roos, 1969b). These fading myths, which impeded cooperation between professionals and consumers in the past, include the fallacies of professional omniscience and professional omnipotence. The veil of secrecy

behind which some professionals conveniently hid information from consumers because of its "confidential" or "traumatic" nature is likewise beginning to evaporate as consumers are demanding direct access to all information required for decision making.

Parents of retarded children are rebelling against being stereotyped as "emotionally disturbed" persons in need of "psychotherapy" or "counseling." Chronic sorrow is becoming recognized as a normal reaction to having a retarded child rather than as a symptom of psychopathology (Olshansky, 1966).

Consumer involvement transcends the participation of individuals in support of their own children and already has impacted on legislation, litigation, and advocacy (Boggs, 1972; Roos, 1972a). Recent legislation has formalized the role of consumers in programs for the handicapped. For example, the Developmental Disabilities Services Act (1971) requires consumer membership on both the state and national councils charged with planning and evaluating service programs. Parents and retarded persons, themselves, are beginning to participate on human rights committees generated by recent litigation (e.g., Wyatt v. Stickney, 1971).

The emerging citizen advocacy programs for retarded persons are placing citizen advocates in roles of monitoring and evaluating services for retarded persons (Wolfensberger, 1972). Formal advocacy projects are blossoming throughout Canada and the United States. Organizations such as NARC have initiated national training programs to implement the citizen advocacy model.

Consumer groups have also begun to insist that programs meet criteria of excellence and that appropriate standards be developed. These groups have, for example, testified before congressional committees regarding proposed legislation affecting the quality, goals, and funding of service programs. The impact of such legislative efforts is evidenced by an increase in Department of Health, Education and Welfare funds directed into mental retardation programs from 14 million dollars in 1955 to 600 million dollars in

The legal and human rights of retarded persons must be recognized and protected"!

The importance of these rights was emphasized when the United Nations General Assembly (1972) adopted the <u>Declaration on the Rights of Mentally Retarded Persons</u>.

Among the specific rights of the mentally retarded persons identified, the following are of special interest:

1 To the maximum degree of feasibility, the same rights as other human beings.

- 2 To proper medical care and physical therapy and to such education, training, rehabilitation and guidance as will enable him to develop his ability and maximum potential.
- 3 If care in an institution becomes necessary, it should be provided in surroundings and other circumstances as close as possible to those of normal life.
- 4 To protection from exploitation, abuse and degrading treatment.

The United Nations action followed the adoption of a similar document by the ILSMH (1968) at an international symposium held in Jerusalem. The rights outlined by the ILSMH became the foundation of many of that organization's succeeding policies and resolutions, including its official conclusions regarding residential care (Roos, 1969).

Unfortunately, violations of the legal and human rights of the retarded have continued into the present (Roos, 1972a). Adoption of laudable "bills of rights" and even the passage of legislation are often not effective in eradicating discriminatory practices. A study by the NARC (1971) indicated no significant relationship between state laws mandating education for retarded children and actual participation of such children in educational programs. Advocates of retarded citizens are, therefore, increasingly appealing to the courts to expedite reform.

Litigation on behalf of retarded persons has spread rapidly among the states (Abeson, 1972; Haggerty, Kane and Udall, 1972; Roos, 1972a; Friedman, 1973; Ogg, 1973; PCMR, 1973). Class action suits have been mounted on the basis of violation of basic constitutional rights, particularly the Fifth, Sixth, Eighth, Thirteenth, and Fourteenth Amendments of the U.S. Constitution. The concepts of right to education and right to treatment have been the two main foci for legal activity. Attempts have been made to define minimal acceptable standards for residential services, and in at least one case (Wyatt v. Stickney, 1971) specific detailed standards were mandated by the court.

The recent creation of several national groups devoted specifically to the issue of the legal rights of the retarded attests to the growing interest in this area. The American Bar Association has formed a Subcommittee on Law and the Mentally Retarded. The National Council on the Rights of the Mentally Impaired has been established by the American Civil Liberties Union Foundation and the Center for Law and Social Policy. The National Association for Retarded Citizens has established a National Legal Advocacy Committee. The National Center for Law and the Handicapped was recently created by joint sponsorship of the National Association for Retarded Citizens, Notre Dame University, Council for the

Retarded of St. Joseph County (Indiana), and the Family Law Section of the American Bar Association. Escalation in legal action on behalf of handicapped persons is likely to catalyze change in services during the next few years, and residential services are likely to be particularly affected.

National standards should be developed to ensure quality of residential services for the mentally retarded.

The precursor of a formal national accreditation procedure was undertaken by the American Association on Mental Deficiency (AAMD), Division of Special Studies (Hubbard, 1969) when it conducted a voluntary evaluation study of 134 institutions between 1966 and 1969. Each facility was evaluated by its own staff and by a small team of "expert" evaluators using standards developed by the AAMD in 1964 (AAMD, 1964).

While this evaluation study was in progress, the National Planning Committee for Accreditation of Facilities for the Retarded was established by the AAMD, the NARC, the UCPA, the Council for Exceptional Children (CEC), the American Psychiatric Association (APA), and the American Medical Association (AMA). The resulting Accreditation Council for Facilities for the Mentally Retarded (ACFMR) joined the Joint Commission for Accreditation of Hospitals (JCAH). Detailed standards were developed by teams of professionals, administrators, and consumer representatives, and the accreditation process began in 1971. Accreditation, which is still a voluntary process, is based on the institution's performance in relation to certain standards and results of a program audit of a selected sample of residents.

The current standards incorporate the major ideological developments outlined above, including normalization, a developmental approach to services, consumer participation and protection of the legal and human rights of retarded persons.

Although the accreditation process is still in a developmental stage and remains a voluntary procedure, its impact on improving services can be considerable. Already federal legislation has been proposed which would incorporate the ACFMR standards into law, and courts have borrowed from the standards in mandating changes in state institutions.

Expanding technology should continue to improve residential services and to decrease the need for institutionalization.

In general, modern technology is not broadly applied. Within institutions the majority of residents is not property served (Hubbard, 1969). Available technology could: (1) significantly reduce the incidence and prevalence of retardation, (2) minimize the need for institutionalization, and (3) increase the degree of independence and productivity of almost all retarded children and adults.

The effectiveness of programs of early stimulation has been demonstrated (Heber, 1972). Behavior modification and its derivative has been particularly successful in helping retarded individuals progress toward developmental goals (Watson, 1970; Roos, 1972b). The advantages of behavior modification for work with retarded persons include: (1) applicability to non-verbal and "seriously disturbed" individuals, (2) implementability by relatively unsophisticated trainers (including parents and direct care staff), (3) effectiveness in minimizing such objectionable behaviors as selfdestructiveness and self-stimulation (4) success in developing highly varied skills including language and basic social skills, (5) applicability in a wide spectrum of settings, (6) suitability for group application, and (7) relative ease of evaluation by quantification of results. Through the implementation of technological advances for residential services the so-called "custodial" model is losing its credibility. Degree of impairment and age are no longer valid reasons for excluding individuals from active programs.

Whenever possible, retarded persons should be integrated into society and participate as fully as possible in the activities of the culture to which they belong.

Generic, rather than specialized, services should serve the retarded whenever practical (Jaslow, 1967). Since inappropriate institutionalization seems to have detrimental effects on cognitive, social, and personality development (Goldfarb, 1945; Spitz, 1949; McCandless, 1964; Zigler, 1961, 1966; Butterfield and Zigler, 1965), every effort should be exerted to prevent premature or unnecessary institutional placement and/or to minimize its duration. This thrust toward decentralization of residential services is consistent with normalization and has been endorsed by the courts under the rubric of the "least restrictive alternative."

Decentralization of multipurpose institutions requires community-based residential alternatives. A multitude of models has been described in the literature (e.g., Helsel, 1971; Wolfensberger, 1971b) and an increasing number of decentralized residential services are beginning to appear throughout the land. Wolfensberger (1971b) concludes his description of types of group and individual residences by stating:

I can see no reason why small, specialized living units (mostly hostels) cannot accommodate all of the persons now in institutions. In turn, I believe that many persons who could be well served in hostels will be served even better in individual placements. Thus, we should experience not only a shift of places from institutions to other group residences, but also a decline in the demand for any type of group residence. (p. 32).

Helsel (1971) describes four pitfalls to the development of decentralized residential services: (1) failure to provide protective services, (2) underutilization of some existing community group residences, (3) lack of acceptance on the part of the community, and (4) federal financial uncertainties. The first of these problems is perhaps the most serious deterrent to parents, who are threatened by the lack of permanence associated with most community residential programs. This area is now receiving increasing attention, particularly from consumer groups (Helsel, 1971).

Other Ingredients

The future of residential services for the retarded will probably reflect the impact of the trends and ideological shifts noted above. The ultimate shape of residential services will also, of course, bear the imprint of changes in the overall fabric of society. Hence many of the technological, sociological and cultural changes anticipated by Toffler (1970) could have major influence on services for the retarded. Indeed, the major ingredients of Toffler's future, i.e., transcience, novelty and diversity, have been directly related to mental retardation services (Roos, 1972a). Residential services for the retarded of the future will be strongly influenced by the degree to which these ingredients predominate.

Technological advances could have major impact on the incidence and prevalence of mental retardation. For example, the need for specialized residential services is likely to decrease if the incidence of profound and severe retardation significantly declines, as Wolfensberger has predicted (1971a). Improvement in procedures designed to foster the ability of retarded persons to function in society could likewise have major impact on residential services. For example, if large numbers of retarded persons showed marked increases in their intellectual ability, then, the need for residential services would greatly decrease. Also, advances in human engineering and behavior modification could revolutionize the design of buildings and training equipment, as already suggested by exploratory automation of training environments (Watson, 1968; Bensberg, Colwell, Ellis, Roos and Watson, 1969).

Shifts in some of society's major institutions could also greatly affect services to the retarded. Multiple marriages, decentralization of the family, proliferation of professional surrogate parents, and the increase of communes could all have important repercussions for institutions. If, as seems probable, a greater variety of patterns of cohabitation becomes normative, more alternative models of community-based residential models will become available to the retarded.

The trend toward greater diversity (Toffler, 1970) suggests increasing tolerance of behaviors currently considered deviant, and growing acceptance of retarded persons as members of society. Indeed it seems probable that the very process of labeling will be revamped to minimize

stigmatizing and negative self-fulfilling and self-limiting prophesies.

Shifting national priorities could likewise alter the course of residential services for the retarded. De-escalation of federal funding for human welfare programs could directly affect the quality and quantity of residential programs. Curtailment of research and manpower development programs could also have major consequences. For example, delay in technological advances could delay decentralization of multipurpose institutions predicated on effective habilitation programs. Legislative developments in such diverse areas as housing, national health insurance, social welfare and vocational rehabilitation could all significantly influence the course of services for the retarded (Boggs, 1972; Roos, 1972a).

Changes in society's basic value system could alter existing ethical, moral and legal concepts to such an extent that the very goals and objectives of service programs for retarded persons could be modified. As individuals gain increasing control over their own destiny through sophisticated technology, questions of values become pre-eminent in shaping the course of history. Questions regarding the ethics of genetic engineering, euthanasia, abortion, sterilization, psychosurgery, behavior modification through aversive conditioning, bio-feedback, cloning, psychopharmacology, and many other technological advances are being debated with increasing vehemence (see e.g., The Hastings Center Report).

The objectives of current residential programs are usually predicated on values which are seldom made explicit and which may at times be mutually inconsistent. Hence, residential services are often based on one or more of the following implicit goals: (1) helping the retarded to develop as fully as possible their human qualities (developmental model and normalization), (2) developing the retarded into economically productive persons as efficiently as possible (economic, cost-benefit model), (3) minimizing deviance (social conformity model), and (4) optimizing happiness and contentment (hedonistic model) (Roos, 1969a). These goals are not necessarily mutually compatible, and they may, in specific instances, lead to divergent service models. For example, the model of the institution as a protective self-contained sub-community can be supported on the basis of a hedonistic rationale while it is condemned by advocates of normalization.

Finally, the cyclic nature of socio-cultural phenomena should be recognized as a factor impinging on service delivery models. The history of institutions during the past century attests to the significant of this phenomenon. The current emphasis on eradicating institutions and normalizing the retarded (e.g., Wolfensberger, 1969b) seems to represent a return to the optimism which characterized the genesis of institutions in the United States in the mid-1800's. If it represents the "peak" of a cycle, then the future might bring a reality somewhat less extreme than that anticipated by those who predict that institutions will "fade away."

Conclusions

The trends in ideology and service delivery systems discussed in this paper can be summarized as specific predictions. The following conclusions are limited to probable developments within the next ten to twenty years. They are specifically applicable to the United States, although they appear congruent with trends noted in many other countries as well (Roos, 1969c). The statements are oversimplified for clarity of exposition, since they generally summarize trends discussed in detail in the body of the paper.

- 1. Residential services for retarded persons will be predicated on a developmental model of mental retardation.
- 2. Normalization, defined as both a process and a goal, will be a guiding principle in the design of residential services.
- 3. Residential services will be decentralized, dispersed and articulated with other community-based services. Retarded residents will increasingly use generic services of all types.
- 4. Residential facilities will be specialized to meet the unique needs of relatively small, relatively homogeneous groups of individuals. The estimate of the desirable size of facilities differs considerably among experts; some consider a capacity of 500 to be an acceptable maximum limit (Roos, 1969c), while others advocate a maximum size not to exceed 20 (Wolfensberger, 1969b). In any case, the size and appearance of residential facilities will be in greater harmony with the communities of which they are a part than is true of the typical contemporary multipurpose institution.
- 5. The "custodial care" model of residential service will be phased out and replaced by models stressing active program ming, transitional services and short term placements.

 Individual placements, such as boarding, foster or adoptive placements, will increasingly serve the long-term residential needs of the retarded.
- 6. Facilities and services will, in general, approximate culturally normative patterns. Deviations from normali zation will result when alternative approaches prove to be more effective in reaching developmental goals. Advances in human engineering and behavior modification are likely to influence the design of specialized environments and equipment.
- 7. Residential services will emphasize small, homogeneous groupings of residents, regardless of the total size of the facility. Private or semi-private sleeping rooms will replace the current mass sleeping quarters and groupings will seldom exceed eight individuals.

- 8. If relatively large facilities survive, staff will be deployed by units rather than along discipline-oriented departments. Institutions which are organized by units will essentially operate as a "cluster" of "mini-institutions," each serving a relatively homogeneous population and staffed by an integrated cadre of professionals, administrators, and direct-care per sonnel, with involvement of volunteers and consumer represent atives.
- 9. Services to the retarded will be delivered by multi-disciplinary teams composed of representatives of professions selected to meet the particular needs of the individuals being served. Professionals will gain increasing flexibility in their roles so that cross-modality approaches (Helsel, 1971) will be common. Administration of programs will be vested in individuals on the basis of demonstrated expertise and administrative skill rather than on the basis of membership in a specific profession.
- 10. The hospital model of residential services will be restricted to the specialized situations serving retarded persons who are physically ill or who require intensive medical treatment. The hospital model will be abandoned and recognized as inap propriate for the vast majority of the retarded.
- 11. National standards will exert increasing influence on quality control of residential services. Evaluation will increase in sophistication and will focus on outcome measures and assess ment of client progress.
- 12. Staff training will assume greater sophistication and will become more successful in modifying staff interaction with clients (i.e., "modifying attitudes"). New careers will evolve to fill the needs for direct-care personnel and to capitalize on community colleges and innovative educational programs.
- 13. Residential programs will develop greater affinity for joint research and educational undertakings with universities, colleges and other agencies. Cost-benefit studies, compara tive evaluations of varied service models and research into administrative and management strategies will flourish (e.g., Budde, 1972).
- 14. The human and legal rights of the retarded will become firmly recognized and current discriminatory, exploitative and de humanizing practices will be gradually eliminated. Protective and monitoring mechanisms, such as human right committees and periodic consumer evaluations, will become regular components of residential services.
- 15. Consumers and their representatives will routinely participate

in decision making, planning and evaluation of total service programs as well as in decisions affecting individual cases. Retarded persons and/or their parents will have increasing options for choosing among alternative courses of action.

- 16. Protective services of all types will proliferate, ensuring stability and permanence to the dispersed residential ser vices of the future. Advocacy systems will assist retarded persons with practical problems of living as well as with meeting personal emotional needs.
- 17. Opinions remain divided regarding the future of centralized institutions. The following quotations reflect the continuing divergence of thought on this issue:

"I hope that we can recognize the fact institutions are with us, they are going to continue to be with us and we had better accept the fact that this is one facet in a total program for the retarded." (Acuff, 1969, p. 19) - Superintendent of a state institution, commissioner of a state agency, and former president of the National Association of State Mental Retardation Program Coordinators.

"The concept of the 'institution' will disappear; instead, a broader concept of 'residential service' will take its place." (Wolfensberger, 1969b, p. 51) - Visiting Scholar at the Canadian Institute on Mental Retardation and prolific author in field of residential services.

"At least two viable models currently embody most principles advocated by the Symposium: the decentralized institution physically scattered within a community, and the simplified community-like institution which maintains active interaction with the community." (Roos, 1969c, p. 26) - Summary of international symposium by the ILSMH.

18. The trend toward increasing diversity noted by Toffler (1970) should lead to an increasingly pluralistic society in which multiple variations of residential services are available to meet the unique needs of individual retarded persons. No single model is likely to meet all needs. To make this as sumption would be to fall victim to Toffler's supersimplification.

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